

Statement by

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Thank you, Senator Craig, Senator Breaux, and members of the Committee, for the opportunity to provide information on family caregiving. In light of your interest in helping older people stay in the community and to help caregivers in their effort to continue caring for relatives and friends as long as possible, I thought I would focus on some of the newest data on caregiving: who are the family caregivers and what do we know about them? What impact does caregiving have on their lives?

DEMOGRAPHICS

First, some basic data on family caregivers:

Nearly one-quarter of US households are involved in family caregiving. This number is important because it shows how involved family members are in caring for one another, and how large an issue family caregiving is in our country. It is a myth that Americans abandon their older relatives to nursing homes. Approximately 80 percent of the care for older people is done by family and friends. Peter Arno for the United Hospital Fund has estimated that in the year 2000 the economic value of caregiving to society was \$257 billion per year—larger than the cost of home health care and nursing home care combined!

The profile of the family caregiver is a 46-year-old Baby Boomer woman who is married and works and cares for her 77-year-old mother who lives nearby. The caregiver spends an average of more than 20 hours per week providing care, and caregiving typically lasts more than 4 years.

THREE TRENDS

Despite the fact that we think of most caregivers as women (and in the past nearly 80 percent of caregivers were women), there is evidence that that trend is changing: the latest research shows that nearly 4 in 10 family caregivers are **men** and, in the workplace, there is a nearly even gender split. This issue is gaining more visibility because employers see a greater impact on their bottom line when both male and female caregivers come in late, take leaves of absence, or take early retirement. Over half of working caregivers of both sexes come in late, leave early, and have to modify their work schedules.

Our recent “Sons At Work” study indicated that men were as likely as women to report that they were the primary caregiver and that caregiving had negative consequences on their work. Men are much more likely to modify work travel and less likely to speak with either their co-workers or their supervisors. Less than half the men in the study had spoken to their supervisors about their eldercare responsibilities. One quote from the study: “Caring for a sick child is an acceptable reason to be taking off; caring for a sick older relative is not.”

In terms of services they would use, more men than women said they would like a geriatric care management service, along with help with legal, financial, and insurance issues.

Another issue is caregiver **health**. Caregivers sometimes sacrifice their own health in their focus on the health of their aging relative. Their desire to be a “good daughter” or a “good husband” and the stress of juggling the roles of parent, employee, spouse AND caregiver can make them

overlook good health care prevention like immunizations and regular physician check-ups. The latest data show that one-third of those providing the most intense caregiving (personal care--bathing, dressing, feeding, transferring--for 40 or more hours per week) report their own health as only fair or poor. This is in contrast to 12 percent of those caregivers with the least level of burden.

In addition, one-third of these Level 5 caregivers doing the most intense caregiving report that their health has become worse as a result of caregiving. Fifteen percent of caregivers as a whole report that caregiving is somewhat or very much a physical strain; and over a third report that it is very stressful.

We can definitely see that the issue of caregiver health is becoming a public health issue as the numbers of caregivers grow and the duration of caregiving lasts an average of four years and longer.

FINANCES

Since 1997 we have seen a 30 percent increase in out-of-pocket spending by caregivers, from \$171 per month on home modifications, groceries, and other financial support to \$221 per month in 2003. We know that family caregivers often speak about the financial hardship that caregiving can place on a family, the decisions that they have to make when choosing to help their parents or their kids—sometimes sacrificing vacations, college, and other things so that they can pay for long-term care. While only one in ten caregivers as a whole says that caring for their family members represents a significant financial hardship, nearly one-quarter of Black caregivers do.

Paying for long-term care can be viewed as especially hard because so few people anticipate that they will have to pay for it. Most people, both Baby Boomers and older Americans alike, think that Medicare will cover long-term care expenses; they also have little idea of how expensive it is. Surveys of the American public's perceptions of long-term care costs consistently show that people believe they will not need caregiving when they grow old and, if they do, it will not cost that much. It is only when families actually face caregiving that they realize the cost in terms of emotional stress, money, and even the toll on their own health.